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Families and Disability



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Families and Disability



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The present paper has been prepared for the IYF secretariat by Peter Mittler, Professor at the University of Manchester and Helle Mittler of Stockport Social Services Division, United Kingdom of Great Britain and Northern Ireland, in their capacity as co-chairpersons of the IYF Task Force of the International League of Societies for Persons with Mental Handicap (ILSMH).

The views expressed in this paper are those of the authors and do not necessarily reflect those of the United Nations Secretariat

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I. Each family is unique

"We all come from families. Families are big, small, extended, multigenerational, with one parent, two parents and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage or from a desire for mutual support. As family members, we nurture, protect and influence each other. A family is a culture unto itself, with different values and unique ways of realising its dream; together, our families become the source of our rich cultural heritage and spiritual diversity. Each family has its strengths and qualities that flow from individual members and from the family as a unit. Our families create neighbourhoods, communities, states and nations."

New Mexico Governor's Task Force on Children, Youth and Families, 1991 [23]

One family in four worldwide has a relative with a disability. These families are as different from one another as any other family. But many such families daily experience discrimination and marginalization in their own immediate neighbourhoods and communities. They are also vulnerable to generalizations about families made by people without personal experience of the actual situation of families. A typical example is the assumption that "a handicapped child means a handicapped family".

The reality is more complex. All families have different strengths and needs. Furthermore, every member of the family also has individual needs, which will differ from person to person, depending on their basic personality, their coping styles and their response to stress in general.

Generalizations about disabled people are as suspect and as dangerous as generalizations about families, and for much the same reason. The experience of disabled people is affected by the social and family environment in which they live as well as by the nature of the disability. Attitudes to disability vary not only from country to country, but also within relatively small areas within a single country. People with visual impairments may be treated very differently from those with speech and hearing impairments. Learning or psychiatric impairments or chronic epilepsy are still relatively the most feared or shunned in both developed and developing countries.

Much depends also on the extent to which disabled people receive the necessary supports, aids and interventions. These range from spectacles and hearing aids, mobility aids, chemotherapy for epilepsy or psychiatric disorders, to schooling and vocational training.

Much of the literature about disability concerns children whose disability was obvious at birth or became apparent at an early age and who are living with their families. In developing countries, a larger proportion of children become disabled after a period of normal development as a direct result of illness or injury (e.g. meningitis, encephalitis or poliomyelitis) or as a consequence of malnutrition. Many more become disabled as a result of road traffic and other accidents, violence, war and its aftermath and as a direct result of abuse. The age of onset and the nature of the impairment will affect different individuals and families to a different extent.

People who become disabled as adults may no longer be living with their own parents but may receive a great deal of support from them or from the extended family. Other adults with an acquired disability may be living a long way away from their families or may no longer be accepted by their families. As a result, many such adults are dependent on the support of the communities where they are living. Local attitudes as well as local services determine whether they continue to be accepted, whether rehabilitation services are available and whether they will be able to resume their work and their place in the community. This applies particularly to soldiers and civilians disabled by wars or armed conflicts, many of whom experience major problems in finding jobs and a valued place in society.

II. Definitions and concepts

Because attitudes to disability are deeply rooted in the social and cultural values of a society, definitions of disability are problematic. Scientists and research workers striving for precision and clarity in the use of terminology have developed complex systems of classification, with the aim of facilitating research and scientific communication. The clearest expression of this trend is the classification published by the World Health Organization (WHO) that is being revised. But the assumptions underlying it have been questioned by disabled people as well as by professionals adhering to a more social model of disability.

The distinction made by WHO [32] in its definitions of impairment, disability and handicap has been widely used and quoted. Briefly, the definitions are as follows:

- An *impairment* is any loss or abnormality of psychological, physiological or anatomical structure or function.
- A *disability* is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
- A *handicap* is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual.

These definitions have been increasingly criticized, particularly by organizations of disabled people on the grounds that they focus too much on the individual with the disability and fail to reflect the extent to which the lives of disabled people are disadvantaged by the social structure of the society in which they live. Although the WHO definition of handicap includes the concept of disadvantage, its origins are located in the individual and not in society and its institutions. These definitions also make no direct reference to environmental or family factors.

Social model of disability

The social model of disability insists that social structures and the barriers to which they give rise need to be modified. For example, there are still countries where a child whose intelligence quotient (IQ) falls below a certain point is denied access to education in schools, either ordinary or special. Similarly, many disabled adults are denied the opportunity of obtaining vocational training or of securing paid employment, not because they have been shown to be incapable of work but as a direct result of negative attitudes by decision makers or because the workplace is inaccessible. For disabled people who are denied access to opportunities and facilities, discrimination is a daily experience.

The social model does not seek to minimize or deny the presence of impairments and the restrictions that these may impose on the independence and autonomy of the disabled person. But it does place more emphasis on the importance of society and its institutions being modified to meet the needs of disabled persons. This contrasts with the traditional assumption that it is disabled people who should be trained to adapt or adjust to society. The models can be seen as complementary rather than as mutually exclusive in meeting the needs of individuals within their own social and family settings.

Terms such as disability and handicap are therefore socially and culturally relative. In an example [13] from Mali:

"The most 'disabling condition' for a woman is to be ugly. This condition is defined in very clear terms. These women do not get married and consequently do not fulfil the normal parental role.

In other countries, dwarfs, people missing an eye, toe or finger or having an extra toe or finger or with a facial disfigurement or albinism may have no functional limitations but still be labelled as disabled."

Helander suggests that disability might simply be defined as follows:

"A disabled person is one who in his/her society is regarded or officially recognised as such because of a difference in appearance and/or behaviour, in combination with a functional limitation or activity restriction."

Disabled Peoples' International (DPI), a world federation of organizations of disabled persons, have proposed alternative definitions:

- *Impairment* is the functional limitation within the individual caused by physical, mental or sensory impairment
- *Disability* is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers

The DPI definition therefore dispenses with the concept of handicap altogether, regarding it as misleading and discriminatory.

Equalization of opportunities

The concept of equalization of opportunities is fundamental not only to definitions, but also to the total process of planning and provision and ensuring the full participation of disabled people in society and in determining their own needs and priorities. It is derived from the Universal Declaration of Human Rights.

The most recent United Nations definition of equalization of opportunities is incorporated in the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, which were adopted by the General Assembly [30] in 1993:

"Equalization of opportunities means the process through which the various systems of society and the environment, such as services, activities, information and documentation are made available to all, particularly to persons with disabilities "

III. What we know and do not know

The quality and quantity of information about disability on a global scale is not impressive and there is some disagreement about the accuracy of such data as are available. The best summary source is the Statistical Office of the United Nations Secretariat in New York, which collects and tabulates information supplied by most Member States of the United Nations. A number of countries have also undertaken detailed surveys and censuses.

It is clear that a major problem in the interpretation of disability statistics arises from the lack of an agreed definition of disability, which would differentiate people with a "marked or significant" disability from people with one that does not seriously impede the day-to-day functioning of the affected individual or that can be easily compensated for (e.g. by spectacles, a hearing aid or a walking stick).

Clearly, such distinctions depend on local customs and attitudes as well as on the availability of aids, appliances and services. For example, people with a mild degree of intellectual disability often participate fully in community activities in most developing countries. In a developed country, however, they are more likely to stand out in schools and may experience difficulty in finding work or taking their place in their local community.

It also goes without saying that in any community much depends on the support provided by the family for their disabled relative in going to school, getting and keeping a job and living with as much independence as possible. In turn, families themselves need support in this task from neighbours and from local services.

Estimates of prevalence

Most of the published information relates to the number of disabled persons in a country and may also provide information about the nature of their disability. However, little or no statistical information about families as such appears to be available on an international scale.

United Nations sources originally estimated the total number of disabled people in the world to be around 500 million in 1990. These numbers were expected to increase to 600 million by the year 2000, which amounts to approximately one person in ten. The figure of 500 million includes 140 million children, of whom 127 million live in developing countries - including 88 million in Asia, 18 million in Africa and 13 million in Latin America. Another 11 million are in North America and a further 6 million in Europe.

These figures are now thought to be an overestimate by the United Nations Development Programme (UNDP). Considering only people with "moderate or severe" disability, Helander [13] puts the current total figure at around 276 million, of whom 183 million are in developing countries and 93 million in developed countries. Helander also estimates that an average of 8.5 million severely or moderately disabled people are added to this total every year, or around 23,000 a day. By 2025, the number of disabled people will rise from 183 million to 435 million in developing countries and from 93 million to 138 million in developed countries. Based on these projections, the total number will be 573 million in 2025, or 8.2 per cent of the world's total population.

Each year, 35 million children die and another 35 million become disabled. At least half of all of these occurrences could be prevented by the use of knowledge and skills already in humankind's possession.

Ninety per cent of infant disability is related to environmental causes related to poverty, which include malnutrition, poor sanitation and persistent abuse.

The global prevalence of specific moderate and severe disabilities is estimated as follows:

<i>Type of disability</i>	<i>Percentage</i>
Movement	2.5-3.0
Seeing	0.5-1.0
Hearing/speech	0.5-1.0
Learning	0.2-0.4
Fits	0.3-0.6
Psychiatric	0.1-0.2
Feeling (hands and feet)	0.1-0.2
Combinations of the above	0.2-0.3

Eighty-five per cent of adult disability is caused after the age of 13. Major causes include domestic and industrial accidents, wars and armed conflict and its consequences (particularly undetected plastic land mines), malnutrition and environmental pollution.

The relative increase in the number of disabled people, particularly in developing countries, can be attributed to a variety of factors. These include not only the rise in the number of births, but also the survival of many children who would previously have died at birth or in the first year of life. This applies particularly to very low birth weight babies and to those with profound and multiple impairments, as well as to children with Down's syndrome or spina bifida who, while not necessarily severely intellectually impaired, are physically vulnerable to respiratory and other infections, unless appropriate medical and nursing treatment is available.

In addition, advances in the quality of health care are associated with increasing life expectancy for both children and adults. Greater longevity in the whole population leads to an increase in the number of older disabled people and in the survival of disabled people who would previously have died at an earlier age. This has clear implications for the need to develop appropriate services to match these demographic trends.

These figures relate to people with marked or significant disabilities. But growing urbanization and an increase in the complexity of educational and occupational demands will increasingly affect people with relatively mild degrees of impairment. For example, European experience in the early twentieth century and current experience in many developing countries indicates that as more children go to school, those who experience difficulties in learning are more readily noticed. Many are still forced to repeat one or more years, thus singling them out as educational failures and isolating them from their friends. Others are simply excluded from school and left to fend for themselves.

IV. Experiencing discrimination

For every disabled person in the world, it is estimated that at least four members of the immediate family will be directly affected through having to adapt to and meet the needs of their relative.

All families will be profoundly affected by the nature of the society in which they live and by the value that that society places on the contribution that disabled people can make. These values are reflected in social structures and institutions that may provide pathways or barriers to disabled people taking their place in the community and making a valued contribution to its growth and development. Just as some families are victims of oppression and discrimination, others have been enriched and strengthened by their experiences both within the family and as a consequence of contacts and supports outside the family.

The extent and the manner in which families will be affected will obviously vary in relation to age, gender, degree of dependence and the amount and nature of the support available from the rest of the family, the local community and service agencies as well as depend on social attitudes and structures.

Most societies and cultures discriminate against disabled people and their families to some degree: in the school, the workplace, on the street and in community settings. Many families have encountered stereotyped assumptions about disability. Indeed, as members of their local and national communities, their initial reaction to the experience of disability may well be identical to that of their neighbours.

Although there are few detailed studies on this subject, the many anecdotal accounts from disabled people and their families, as well as the accounts by a range of observers suggest that many people still regard disability as a direct result of magic or of some transgression earlier in life or in a previous life. In many countries, attitudes towards disabled people and their families are still affected by myths and superstitions. These are widespread in the society and are by no means confined to rural areas or to people without education ([16] and [27]).

At one extreme, typified in mid-twentieth century Europe, disabled people have been systematically exterminated or permanently incarcerated in institutions. In many developed countries, people with psychiatric or intellectual impairments have been kept in appalling conditions, often without treatment or rehabilitation and with little or no prospect of a return to the community. Some have been (and still are) subjected to compulsory sterilization or been forced to take part in noxious and illness-inducing drug trials. Many are victims of emotional, physical and sexual abuse.

Just as the Incas banished disabled persons from their cities on festival days, there are still reports of similar practices in some modern States on special occasions such as an international sports event or the visit of a foreign dignitary. There are areas of the world where pregnant women are warned against the risk of encountering a disabled person because of the risk to their unborn child.

In many countries, disabled people are still isolated from the community and denied access to its resources and facilities. Many have been excluded from work not because their condition precluded work but simply on account of the presence of a disability or because the workplace is not accessible or unsuitable for a disabled person.

Disabled people and their families are also subject to all other forms of discrimination, as are non-disabled members of their communities and countries. Discrimination and disadvantage relating to a family member with a disability may be increased if he or she belongs to a minority

ethnic group; if they are female; if they are a member of a low socio-economic group; if they have a minority religion; if they are homosexual or lesbian. Some family members with a disability may therefore be subject to multiple severe discriminations and disadvantages.

Poverty is one of the most common forms of disadvantage experienced by disabled people and their families. Disabled people in all countries are economically disadvantaged. Many are living in severe poverty at or beyond the margins of society. This applies also to disabled people in countries with advanced systems of income support, because the allowances available to disabled people are judged to be inadequate to meet basic living costs. An official study in the United Kingdom showed that families of children with disabilities have incomes that are on average 22 per cent lower than those of equivalent families in the population as a whole [26].

The costs of meeting the needs of a disabled person will vary considerably but many studies have demonstrated the need for additional expenditure of clothing (particularly footwear), laundry, transport and additional furniture as well as replacement costs where children may be destructive of household furniture and fittings.

These are examples of direct costs but there are even greater indirect psychological as well as financial costs that arise from the inability of one or more family members to be free to obtain paid employment. It is almost invariably the mother who is prevented from working outside the home, reflecting the stereotype of the community and of the family that it is the mother who must, by definition, be the main carer. In the study of the United Kingdom mentioned above, 32 per cent of parents had no earners within the family unit, compared with 18 per cent of the general population of parents [26].

Yet there are a few societies in which disabled people and their families are regarded as full and equal members of their local community and where the birth of a disabled child may be seen as a special gift of God. There are reports of disabled people in Samoa being included in ceremonial dancing and blind people being regarded as being under special divine protection in rural areas of Mexico [9].

A detailed study of proverbs, poems, riddles and folk-songs from Kenya and the United Republic of Tanzania involving references to disability, and interviews with tribal elders and with primary and special school teachers noted that most of the elders attributed disability to God's will or witchcraft and did not believe that education had anything to offer, whereas most of the teachers referred to illness and felt that education would enable children to be accepted and to make a contribution to society [16].

Kisanji concludes that:

"Difficulties notwithstanding, the communities accepted the presence of disabled persons in their midst as part of a continuum of individual differences which must be tolerated, respected and its members assisted to develop within the cultural boundaries."

"The Masai do not stigmatise people who have a disability, however serious the condition may be, by excluding them from the community. Disabled people marry, become parents and perform many other tasks [29]."

Another well-documented example of community acceptance and inclusion is the island of Martha's Vineyard in Massachusetts where a large number of the population have a hereditary form of hearing impairment but where the whole population are easily able to communicate through American Sign Language [10]. In fact, normally hearing families are reported to use sign language when they do not want their children to understand a conversation.

Combating discrimination

Fortunately, individual families, as well as individuals within families and groups of families working together have themselves, in a variety of ways, worked to modify negative attitudes and striven to secure the acceptance of disabled people into the community. The extent to which they have succeeded varies greatly not only from country to country, but also within countries.

Growth of voluntary organizations

The 1940s and 1950s witnessed the spontaneous development of groupings of parents and family members. At first, these groups provided a foundation for mutual support and learning and a sharing of ideas and experiences. But many developed into effective forces for change, first at the local, then the national and finally at the international level. Their members were not only determined to gain access to basic supports and services for their relatives, but also to create better conditions for families with similar needs in the future. Over the years, they have campaigned vigorously for changes in legislation and provision and often became powerful advocates for changes in social structures [7].

Public attitudes

Voluntary organizations and family members have been at the forefront of the movement to bring about changes in public attitudes to disabled people. They have done so partly by their own example and partly by attempting to influence the way in which disabled people are portrayed in the media: in local and national newspapers and on radio and television.

In general, disabled people are now less often depicted as helpless victims, needing the charity of the public or as fighting bravely to overcome their disability. More and more the emphasis is on their similarity to other people, rather than on differences. Similarly, families are less often depicted as overburdened and handicapped by having to look after a disabled relative. The emphasis is more on the supports that families need in order to help the family as a whole to lead an ordinary life. However, there is still a long way to go in all countries before disabled people and their families are depicted in ways that they themselves can accept. International organizations such as ILSMH have produced some helpful guidelines to this end [28].

Development of self-advocacy organizations

During the 1980s, groups of disabled people themselves began to form their own organizations and to distance themselves from bodies that claimed to represent their interests but that were in fact controlled by a majority of non-disabled people.

Some of these organizations are now highly influential bodies that operate at national and international levels. The best known of these is DPI, which was founded in Singapore in 1981, with some support from the United Nations, as a direct consequence of the International Year of Disabled Persons: "Full participation and equality" (1981). It draws its membership from organizations of disabled people at the national level and also has strong regional networks.

DPI has been highly influential in the United Nations and played a major part in the development of the World Programme of Action concerning Disabled Persons (1983) and in the launch of the United Nations Decade of Disabled Persons (1983-1992).

The self-advocacy movement tends to be led by articulate or well-educated people with physical, sensory or invisible impairments. More recently, people with intellectual disabilities have also started to develop self-advocacy organizations (e.g. People First) though it is still common for families to advocate on their behalf.

There is a potential source of tension between advocacy and self-advocacy organizations. Organizations of disabled persons wish to speak for themselves and tend to resent and reject statements made on their behalf by organizations for disabled persons. "Nothing about us without us" is the slogan of DPI. However, there is no reason why organizations of disabled people cannot make common cause with other organizations, provided they perceive common goals, and they will be seen to be more effective in securing their aims if they work together rather than separately.

Within families, too, there is a natural tendency for non-disabled members of the family to represent the interests of their disabled relatives, especially if they are children or have significant difficulties in speaking for themselves (e.g. as a result of severe intellectual or language impairments). Many examples of such a tendency can be seen in ordinary social encounters; disabled people have frequently complained that people "talk over the top of their heads", literally if they are in a wheelchair or figuratively in other situations. Many people address the carer or family member in situations where it would be more appropriate to ask the disabled person directly. This is sometimes described as the "Does he take sugar in his tea?" phenomenon, the title of a weekly radio programme in the United Kingdom.

V. Experience of families

Although most disabled people live in families, very little published information or research is available on the situation of such families worldwide. A number of symposia have been held in which reports from different countries have been presented under specific headings (e.g. legislation, family support systems, basic social welfare provisions, respite care etc.) and then analysed for common themes [9]. Despite major cultural and social differences, a number of common themes do emerge from such comparative studies.

Despite the shortage of international and comparative studies, there are many published examples from individual countries in which family members including disabled people have spoken and written eloquently about their needs and aspirations and about the improvements that they would like to see in the ways in which their needs are met and not met.

The stories they tell are not all about isolation, prejudice and discrimination, numerous and moving though these are. They are also about shared learning and growth, about the enrichment of experience of all family members and about the joys of achievement and success. The experience of disability can be positive and often adds a new dimension to the lives of individuals and families.

Family stories collected by a Task Force

ILSMH has set up a Task Force to ensure that families who have a relative with a mental handicap are included in activities for the International Year of the Family (IYF) at the local, national and international level. The Task Force consists of one mother and one father from each of the main regions of the world. In order to raise public and professional awareness of the situation of such families, the Task Force has collected a wide range of family stories from the main regions of the world. In addition, members of the Task Force have devised a series of Learning Messages specifically for IYF. These are reproduced in the annex. Although the experience of most members of the Task Force concerned mental handicap, it is felt that both the family stories and the Learning Messages are equally relevant to all disabled persons and their families.

Nearly all Learning Messages demonstrate families' strengths in combating difficulties and discrimination and their ability to learn and develop positively, gaining from their experiences, however difficult and painful they may be. Many, if not all, of their experiences will be similar to those of families with members who have other kinds of disability.

Information given to families

The situation of the families and the condition of their disabled member were found to vary a great deal. Some disabilities had been diagnosed at birth; others were a result of illness, an accident or war. However, learning about the disability presented the first common difficulties. It often took months or even years to obtain an accurate diagnosis, even for families with money, a high level of education and some medical knowledge. Local doctors, even paediatricians were often too ready to offer reassurance that a child who was demonstrably delayed in development would "be all right" or "catch up later". Parents themselves, understandably, wanted to believe this statement and felt unable to challenge it, even when they felt sure that something was wrong. Only the top national hospitals and facilities seemed to have the necessary expertise to assess and diagnose correctly.

The experience of being told that their child is disabled is usually an unforgettable experience for most parents. Parents valued the rare occasions when the specialist told them with sensitivity and enabled them to retain some hope that their child could learn and develop. Too often this was

not the case and doctors gave a globally negative picture, telling parents and grandparents only what the child would not be able to do. To these families' credit and the credit of the member with the disability, these gloomy predictions were often disproved.

In Muslim and many Asian cultures, only the father as head of the household was given the information about the disability. Many fathers carry this knowledge alone for weeks, months, even years before they are able to share it with any other member of their family, often another male member and before telling their wife. One Korean father waited for 10 years before informing his wife about the diagnosis he had been given shortly after his son was born.

Advice and support given to families

Very often parents are not given advice about how they can help their child to develop when the disability is diagnosed, nor are they offered adequate support. In developed countries, there is now an understanding that the effects of impairment can be minimized by the provision of learning programmes and appropriate technical aids from the earliest stage. Because of this, support and advice are often offered and educational programmes are available from the age of two years or even earlier. In some developed countries, such as Italy and the United States of America, all children, including the most severely disabled, attend mainstream schools, which is resulting in greater understanding and acceptance from others [24].

In developing countries, access to such support is often rare and problematic. Many families receive no advice or support until their child is of school age, if then. When they seek school or pre-school facilities, they often encounter rejection or teachers who are untrained or unequipped to enable their child to learn. In the local schools, their children are often taunted and even bullied.

In many countries facilities to teach disabled children with learning, sensory and/or behavioural difficulties were set up initially by parents and parent groups themselves. Many mothers of these pioneering families trained as teachers of children with special educational needs and began to help other children and other families as well as their own. Once appropriate educational and, later on, vocational provision was made available, families almost universally reported progress in learning and development. However there is sometimes a mismatch between the diagnoses given and the intelligence test results and the level of progress achieved. Some children assessed at a very low IQ level progress well and achieve considerable independence in self-care skills while other children with a higher tested IQ make little progress ([1] and [20]).

Roles of family members

The day-to-day care that disabled children need varies greatly and depends both on their level of impairment and on the social environment, circumstances and attitudes among which they live. Some young children need much more intensive care because of sleeping, feeding and health difficulties.

Almost universally, responsibility is most likely to fall upon women, usually mothers. Working mothers often give up their jobs to care for their disabled child. In China, after the mother's statutory maternity leave, grandmothers often take over the caring task. Older sisters too have an important role to play and some research suggests that they are the most likely to be adversely affected among brothers and sisters.

While in some cultures the father's main role as a parent is that of breadwinner, there is now greater variety in the way in which fathers parent. In many families the roles are more shared and in cases where both parents shared their fears and feelings and also the care of their disabled child and other children, this also seemed to contribute to a more positive view and outcome. In a minority of families, fathers or grandfathers were the main carers of their disabled child, particularly where this was a son who needed intimate personal care.

A common situation is that of women as single parents, either as unmarried mothers, separated or divorced or widowed parents. Unless they are well supported by their families or communities or are wealthy enough to buy support, they are likely to be among the most financially disadvantaged families.

The reaction of extended family members and of friends and local communities to a disabled child or adult and their family will vary greatly, depending on the values and beliefs of the society in which they live. Where families are shunned or rejected, this can put an intolerable strain on family members and lead to extreme experiences of isolation and depression. It can also exacerbate marital difficulties and result in separation and marital breakdown.

Where families are supported at least by some members of the extended family and community, this makes a very significant difference to their lives and to the opportunities for the disabled child or adult to interact and have access to ordinary everyday experiences. Supervision and even some practical tasks can be shared, which enables the mother and brothers and sisters also to have some time to participate in the life of the community and to pursue their own interests. Parents and family members greatly appreciate and value such support and count themselves very fortunate to receive it.

Families with a disabled member are often themselves educators in disability issues within their own families and communities. Through their interaction with others and by giving explanations to neighbours and friends, even by involving neighbours and friends in local associations and training events, they are instrumental in raising awareness about disability and in helping the community to increase its knowledge. Contact with disabled children or adults can often enable others to enjoy the relationship when they get to know them and appreciate their personal strengths and qualities.

As their child grows older, families begin to think about the future. Often it is at the stage of adolescence that parents' hopes and expectations for their disabled son or daughter begin to contrast most sharply with those for their other children. Sometimes this in itself leads to pressure on mothers to produce more "normal" children and (especially in some cultures) sons to carry on the family name and tradition. In one such case, a mother was persuaded to have eight children, seven of whom were handicapped.

Parents would like their sons and daughters to live as normal a life as possible; to earn their livelihood through employment; to marry and have friends; and to live in their own accommodation with the support they need to lead safe and full lives. In many parts of the world where sufficient local or State services do not exist, families with means band together to set up vocational schemes and, increasingly to set up trust or insurance schemes to provide for their children when they are no longer able to care for them. Often they are again discriminated against in these areas. Few insurance schemes will offer schemes for people with disabilities. The majority of families do not have the means to contemplate any such schemes. Indeed, some have to resort to exploiting their disabled child or family member as beggars, where they are often prey to unscrupulous entrepreneurs.

Many parents look to their non-disabled sons and daughters to provide for their disabled brother or sister. However, both parents' and brothers' and sisters' attitudes to this varies considerably. While some families take this approach for granted, others are very reluctant to place such a major responsibility on their children, who may already have difficulties of their own. Some children who may be the only sibling are also apprehensive and resent the fact that they themselves will receive no support in this task.

Many parents feel the need for facilities when they themselves will no longer be able to provide the necessary care and support to their older family members with a disability. The few institutions that exist are often isolated from family life and do not allow for regular easy contact. Stories of older disabled family members included that of a mentally handicapped man in his

sixties who had only recently re-established contact with one brother and whose sister attended his funeral after not having seen him for over 50 years.

Effects on family members

Often there are no major differences to family life. If the disability is not severe, multiple or progressive, it need not interfere with the normal daily routines or with the way families live their lives. Some disabled children, young and older people are well integrated members of their communities, with rewarding relationships and lives that they enjoy and that enrich others. Often they make a valued contribution to the economic and social life of the community. Some disabled people are key members and leaders in their fields, whether it be political, scientific or in the arts. They too are often influential in changing attitudes and social structures for the benefit of disabled people and their families.

Sometimes, however, the interplay of the social environment and severe and/or multiple impairment leads to some restrictions on family life. In addition to the isolation and the increased intensity of caring already mentioned, family members also report an inability to go out or undertake activities spontaneously, as would other families, unless there are supportive relatives, friends, neighbours living locally or local supportive services that they can access.

The time that parents need to look after their disabled child or relative clearly also affects the time available to devote to their non-disabled children and to each other. Some families do think that their non-disabled children are neglected or held back as a result of this. Sometimes, when the needs of all the family members cannot be balanced adequately and the strain is too great, there is family breakdown and either parents separate or disabled children are sent to live outside the family. This can also happen because there are no adequate educational or vocational facilities locally. Again, this affects the closeness of family relationships. But it may have some advantages. As a disabled African leading figure explained, he would not as a non-disabled person have had the advantages of an international education, which enabled him to reach a high post and later return to visit his farming family.

The role of grandparents is often very influential. They can be most supportive and share the care and take a lead in seeking expert opinion and advice, as in a Chinese family that was interviewed. They can often provide support financially and emotionally. They can also be rejecting and oppressive: in blaming the mother; in hiding the truth about a history of disability in the family; in putting pressure on a mother to ignore medical or educational advice or to have more children. Aunts and uncles and other extended family members can also play similar roles.

Brothers and sisters can develop warm, loving relationships with their disabled sisters and brothers. They may be the best at understanding them when there are communication difficulties; they may become playfellows. They can be supportive when the disabled child starts school or is taunted or bullied at school. But if this happens then they too can suffer. Some children take on some of the attitudes around them and become ashamed to bring their school friends home to meet their disabled brother or sister and in turn became isolated and withdrawn. Some are disturbed in their activities or their studies by their disabled brother or sister, especially in crowded accommodation.

A key factor seems to be how or whether the disability is explained to them. Some parents are reluctant to do this for a variety of reasons but when explanations are given from an early age children seem better able to cope, perhaps because the parents are sharing their own ability and positive attitude. Being involved in activities and programmes with their disabled brothers and sisters also seems mutually beneficial.

In countries where the standard of living is comparatively high and medical services are more advanced and better equipped, the number of older disabled people are increasing with the increase of life expectancy. This has led to situations where ageing people whose own infirmity

may be increasing being in a position of caring for their own disabled parents or other older relatives. The marked increase in the number of older people, who may soon be more numerous than the number of employed people to support them, poses a new and as yet unfamiliar problem both socially and economically for the next millennium.

There are, indeed, important benefits to living with a disabled child or relative. Nearly all parents or family members, no matter how painful or difficult their experiences are or have been, report on important fundamental gains. Many of these relate to knowing and loving the person with disability for his or her unique and individual personality. Many recount with pride the many achievements their child or relative has made in developing independence and in contributing to society. Many report how much such persons are loved and appreciated in their local community. However, there are important gains beyond these.

Some people express this in terms of gaining a different perspective in the way they see life and relate to other people: their experience has given them a new dimension of understanding and humanity. They have shed many of their previously held judgements and are better equipped to understand other disadvantaged people, whether they are disabled, poor or socially weak. Previously, they were critical and perhaps arrogant in their judgements; now they feel better able to understand. Some parents, indeed, offer support and advice to others.

Families' experience of professionals

Throughout the life of a disabled person, the family can come into contact with a variety of professionals. Parents and family members are appreciative of those professionals who:

- Treat them and their disabled child or adult relative with consideration and respect
- Communicate with them openly and honestly
- Share their information and skills
- Give clear and full explanations:
 - (a) Of their role and their agencies' responsibilities
 - (b) The legislative framework in which they operate
 - (c) The disabled member's rights and entitlements
- Advocate on their behalf or alongside them for better service provision, more relevant and humane policies and social and economic conditions
- Explore needs and plan services in conjunction with families.

In many countries there are good examples of true partnership between professionals and family members working and training together and jointly combating discrimination and disadvantage.

However, this is still the experience of only a minority of families. Too many families still complain of inadequate information, both oral and written. When information is given, it is often in a language full of professional jargon, which families have difficulty in understanding. An overly negative view is taken of their disabled child or relative and of themselves. They are often excluded from assessments when these are undertaken and from decision-making and planning when services are delivered. These may be offered on a take-it-or-leave-it basis, with little possibility of choice or negotiation. When consultation does take place, it is often felt to be on an unequal basis and only to a point before "the barriers come down".

Direct communication with the disabled child or adult is not always, or even in the majority of situations, the norm. Even where the law insists that the disabled child or adult's views must be sought, there are limits to how seriously these are considered, especially when there are intellectual impairments or when professionals find it difficult to understand the disabled person.

Low expectations remain a significant form of discrimination and result in reduced life-enhancing opportunities for many disabled children and adults. The arrogance, lack of understanding, insensitivity and judgemental attitudes of some professionals add considerably to the distress of many families.

Many disabled people, parents and other family members, especially those disadvantaged by poverty, low levels of education and low class or status, remain in awe of professionals. Dependence on professionals for those services that exist makes it difficult and risky to challenge their assessments, views and decisions. However, with the gradual growth of United Nations initiatives to promote the rights of disabled people including disabled children and the development of strong parent and self-advocacy groups, families are growing in confidence in their own knowledge, experience and skills and, above all, in the knowledge of the rights of their disabled members to equal social justice. New assertive generations are emerging to claim and work towards these rights, preferably in partnership with professionals but, if this partnership is not forthcoming, without them.

Disabled people and their family members have always had an informal role in raising the awareness of professionals in relation to the experience of disability in society and to their needs. Many parents explain to teachers and other professionals how to communicate and respond to their children and also how to explain this to other children and parents. Relatives of older disabled people do the same. In many countries, family members now play an active role in the formal training of professionals.

Recent reviews of research on parental needs has suggested that professionals need to adopt a much wider and more comprehensive perspective in working with families [19]. For example, professionals would be well advised to inform themselves about existing family and social networks, the extent to which individual family members are able to support the child and the parent(s), particularly mothers. Families also differ greatly in their coping style and in their ability to obtain support both from the rest of the family and from their existing social networks. Professionals need to learn to take these factors into account in assessing the social and family context within which the child is living and developing. In the words of this author [19]:

"Families differ greatly not only in how they organise themselves and in the resources that they have but in how they perceive the challenges they face. The same event will have different meanings and different effects for different individuals. Ultimately, the implication is that families differ in the types of services which they will find most helpful in supporting their own coping strategies."

VI. Implications for policy and practice

The experiences that families have reported throughout the world have profound implications for the ways in which services for families are planned and delivered.

In the following section, examples are given of ways in which professionals have tried to develop services in ways that are more responsive to the needs of families. Attempts have been made to do this by listening to parents and family members and by seeking to work with them on a basis of partnership and equality, where each has complementary expertise.

Access to information

One of the foremost needs of families is for accurate and honest information about the condition of their family member. This may be at the time of birth, if the disability is already apparent; or when it becomes clear that a child's development is delayed or at any time of life when disability is the result of illness or accident, malnutrition, abuse or war.

Because "knowledge is power", information enables family members to begin to understand their situation and to make choices about what they can do to minimize the effects of the disability on their member's and their own lives. However much of a shock a diagnosis may be, it is often more helpful than uncertainty.

The information that families need is much more than a diagnosis or an account of what impairment is present. Adequate information will include some explanation of biological processes in clear lay language and also some idea of the range of possible prognoses for the person with the disability. An exclusive focus on what the person will not be able to do is experienced as destructive and unhelpful by families. It is even more important to know what they will be able to do and that they are given the range of possibilities, from the most pessimistic to the most optimistic view of the future.

Families also need information about what options for services and supports are available to them. These should include local, regional, national and international organizations; health, education and welfare services; employment and vocational opportunities, as well as informal networks.

The manner in which information is given is almost as important as the information itself. A number of guidelines are offered below, drawn from various sources.

The knowledge gained from assessment, whether it is medical or educational, should be shared with family members as early as possible.

Family members should not, in general, be told alone.

Because such information is likely to be upsetting, telling parents or partners together or enabling a parent to have a relative or friend present is supportive and will enable such support to continue.

The fact that such information is not easy to give or receive should be acknowledged.

There are cultural differences in how emotions are expressed but it is helpful to give opportunities for family members to express their feelings privately and to encourage them to share their feelings with others whom they can trust.

It is important to give opportunities for the first "telling" or information-giving to be repeated or followed up.

If such information comes after birth or a trauma, such as an accident or sudden illness, it is likely to be a shock. In such cases, the information that is given is unlikely to be fully heard or understood. It is therefore important to give some information in writing and to arrange for a second appointment or for a professional such as a doctor or nurse or social worker to visit the family a little later to explain anything that was not understood or to give further information in response to questions that the family want to ask after reflection.

Professionals should demonstrate a positive approach, which reflects respect and valuing of the child or person with the disability. Information should be given honestly but with an emphasis on positives.

Families of disabled persons consistently express the need for a single point of contact to ask for information or advice. Their needs cross traditional departmental boundaries between departments of health, education, housing, social welfare, vocational training and employment.

Practical advice

Although families value information, they also say that information alone is not enough. They need, from the earliest days, some guidance as to how to support their disabled family member and, wherever possible, how to minimize the disadvantaging effects of the impairment.

Parents of young children appreciate advice on how to stimulate and help their child to learn, explore and socialize. At each age and life stage, there are both common life needs such as the need for loving relationships and a sense of self-worth and security. There are also likely to be particular needs that have to be met: educational needs; sexual and vocational needs; and accommodation and care needs when family members may no longer be in a position to offer the necessary support and care themselves.

Professionals may be able to offer such advice themselves or be in a position to direct families to other agencies or organizations who can. Other parents of disabled children or families with a disabled member are often able to support others facing similar issues.

Family support

Many families with a disabled child or adult member live their lives and cope in much the same way as other families. However, the availability of support from family, friends, neighbours and communities is a crucial factor in how they do so.

The support that families need and value takes many forms and includes support from informal social networks, local communities and governmental and non-governmental agencies.

Attitudes

The acceptance of and liking or love for the person with the disability is central. Positive attitudes among their family members or from neighbours are of great importance. Families are often instrumental in generating such positive attitudes themselves by giving the people around them an opportunity of getting to know the disabled person.

Practical help

Caring for a disabled child and adult usually takes more time and effort than caring for those without an impairment. In such situations, any help with practical tasks may be supportive, whether it is help with other household duties; help with other children in the family or help in caring for the disabled person, which again may take many forms. It can include looking after the disabled person in the home while other family members are engaged in other activities; undertaking a particular programme with the disabled person to enable him or her to acquire a new skill; or taking the disabled person out of the home for particular activities and experiences to broaden his or her life.

Practical help in the home may also take the form of special aids such as wheelchairs and appliances, and adaptations to the home, such as hoists or wider toilets.

Respite or shared care

The term "respite care" is problematic, since it again reflects the model of disability being an inevitable burden from which relief must be given. Terms such as "shared care" or "alternative or second families" are increasingly being used. Similarly, the concept of care may be too limited and under-emphasize the positive aspects of stimulation, new experiences and enjoyment associated with family life.

In a number of countries there are schemes whereby a family with a disabled child or young person is linked with another family who gets to know the child and invites him or her to stay at regular intervals or from time to time. This gives children with a disability an opportunity of mixing with different children and adults in a different environment and of broadening their experiences. It also enables them to gain greater independence from their own families. At the same time, it gives their own families the opportunity of participating in activities that the disabled member might not be able to undertake or of giving more time than they are usually able to give to other members of the family.

A major national study in the United States showed that although 46 out of the 50 States provided shared care in some form, many families experienced problems in being aware of what was available and in gaining access to the service of their choice [2]. Many of the arrangements were inflexible and failed to meet families' needs. Examples of accessible family support systems from the United Kingdom have recently been reported [25].

In addition to benefits for the family or for the individual, such schemes bring benefits to the community as a whole. Families who offer to share their home with a disabled child or adult demonstrate their commitment to the sharing of such roles and tasks by the community as a whole. They also provide valuable examples to neighbours and fellow citizens.

Financial support

When a family includes a disabled member, the family almost always experiences additional costs. In many countries, financial support is offered only by other members of the family or in some societies by the disabled child or adult begging for alms.

In many developed countries, social welfare provision acknowledges a responsibility for all citizens to support those who are vulnerable and disadvantaged. The State offers some financial support to those who care for disabled children or adults in their family and who may, by so doing, forego their own work or career opportunities. Care within the home is also often seen as a more desirable and certainly also as a cheaper form of care than alternative residential care if such support is not available.

When disabled persons reach adulthood, they are also entitled to financial support if they are unable to work or support themselves financially. This includes the cost of any support they need to live in the community, including staff to support them in practical ways by helping them with personal care, shopping, cooking, cleaning etc. and additional costs for travel.

Some families themselves are taking out insurance or setting up trust schemes for their disabled sons and daughters for the future when they are no longer able to offer such children the care they need.

Counselling

In addition to practical support, families or individual family members sometimes need and can benefit from psychological support, particularly when negative reactions to disability persist and/or become overwhelming. Counselling is a broad term to describe a number of methods of offering such support. The main principles include helping people to express their feelings and thoughts, however negative these may be, in a supportive, non-judgemental environment and to help them to look at all the choices available to them in order to work out what they think is best for themselves and their family. This type of support service is available only to a limited number of people in developed countries and those wealthy enough in developing countries to find and pay for such a service.

Family-to-family support and self-help

Almost all services and policies for disabled people and their families have their origins in families and family members coming together and supporting each other; in initiating programmes to help their disabled children and relatives; and in pressing Governments for social policies to give them the support and services they need.

Families have a unique ability to support others in a similar position to their own. Although all families are different, they can understand better than others the experiences of caring for and living with a disabled family member in their social context and environment. They can empathize with each others' feelings; share ways in which they themselves have coped with any difficulties that arose and how they sought and found solutions. They can be a source of information and advice and offer mutual practical and emotional support. Some of the types of support described in previous sections may be offered by other parents and family members.

Different family members can gain support for their particular situation and role from others: mothers, fathers, grandparents, brothers and sisters. Disabled people gain from the friendship of other disabled children and adults who have had similar experiences of struggle and achievement and of facing prejudice and disadvantage.

Much can be gained from groups and associations of disabled people meeting together and from other family members and families meeting in groups and associations. Not only is there a pooling of knowledge and experience and a breaking down of feelings of isolation, but also such groups can gain strength from each other in initiating new methods of support; in modifying the attitudes of others; in advocating for the rights of people with disability and their families; and in pressing for more appropriate policies to address these rights.

Self-help groups can be appropriate and helpful at any age or stage in the life cycle of the disabled person and his or her family. Children gain from sharing activities; adolescents and young adults from discussing views and experiences as well as having fun together; older people gain from meeting and sharing memories of their past lives, as do all older people.

Groups of parents can meet in each others' homes, in community halls and, as happened in Côte d'Ivoire [11], in the local market-place.

Self-help groups can also invite professionals to give them information, advice or support. They can involve professionals in advocating on their behalf or jointly press for improvements. They can also demonstrate their own abilities to contribute to the training of professionals.

Conflict and advocacy

Conflict may arise from time to time in all families, particularly when children reach the adolescent or young adult stage and may make choices different to those favoured by their parents. Most young people will grow in independence and make their own way. The degree to which they take account of their parents' views and wishes will vary from culture to culture and from individual to individual. This development is even more difficult for those young people who may remain dependent for their physical care on their families throughout their lives.

Common areas for potential conflict include young people's wish to experiment and take risks and try new experiences, even if these are later discarded as mistakes. Young disabled persons may wish to go further afield than their families consider safe; they may wish to try new skills; they may, like other young people, want to form sexual relationships; they may want to marry and to have children of their own.

Their parents and relatives may well be sympathetic to these choices and wishes; they may, indeed, encourage them. However, in other families, young persons may meet with discouragement, disapproval and blocking of their wishes. This negative response may spring from the best of motives: other family members may fear for the disabled young person and wish to protect him or her from harm, upset or emotional pain. However, this may nevertheless constitute a denial of the right of disabled persons to self-determination and to make choices about their own lives.

Similar conflicts may occur when disabled persons are older. They may also want to do things that other family members feel may constitute a risk to themselves.

In such situations, it is important that disabled children, young people and adults have access to an independent person who will act as their advocate and who will argue their case, try to ensure their rights and enable them to exercise control over their own lives. This may need to be done at the same time as offering some support, advice and/or counselling for the rest of the family.

Abuse and protection

Even more serious and difficult are those situations in which disabled children or adults are abused. While the majority of families care adequately or well for their disabled members, there are family situations in which the disabled member may be scapegoated, neglected or ill-treated.

There is now a growing body of research, at least in developed countries, about the abuse experienced by disabled children and adults. People with disabilities, including older people, have also expressed their feelings and views about their experiences of abuse, which in some cases may have occurred many years ago.

Sexual abuse has been reported in most cultures and all classes of society. As the pre-conditions for the occurrence of sexual abuse include both the accessibility of a more vulnerable person and the ability to ensure their silence about the abuse, it is clear that these conditions are present in relation to disabled people.

Studies in the United States have estimated that abuse has occurred in up to 25 per cent of adolescents with learning difficulties; 50 per cent of young people in institutions with hearing impairments; and as many as 50 per cent to 75 per cent of children with severe learning

difficulties and behaviour problems ([15] and [31]). In the United Kingdom an estimated 5 per cent of adults with learning difficulties have been sexually abused at some time.

There are many reasons for this. Some relate to the negative social attitudes of prejudice and discrimination that lead parents of disabled children to neglect or ill-treat such children or even leave them to die. Family members may adopt the social attitudes and behaviour of others and taunt such children, and criticize or reproach them for their difference and for what they cannot do.

There are many different forms of abuse; abuse is also cumulative and multiple. All sexually abused children and many physically abused children are emotionally abused. About a quarter of the children who are physically abused are also sexually abused. Once a child has been sexually abused he or she is more vulnerable to further abuse.

There is a growing recognition that the abuse of disabled children and adults occurs all too often and more frequently than in other populations. Such abuse occurs not only within families, but also in institutions and with alternative families and carers.

The very dependence of the disabled member may make him or her the target for all the frustrations caused by a variety of stresses in the family such as poverty, overwork, tensions in family relationships, unemployment, poverty and ill health.

Lack of knowledge may also lead to some forms of mistreatment, such as emotional neglect and lack of stimulation, that are likely to affect significantly the disabled person's degree of disability in coping with his or her environment.

Disabled children and adults are perhaps the most vulnerable to abuse of all kinds including severe physical and sexual abuse. Disabled children and adults often require more intimate physical care that enables others to have access to them in private. They may have less access to sexual education and to an understanding of what is normal and acceptable touching and what is sexual behaviour. They are often less free to move about and find independent people to whom they can talk about the abuse and they may also find it harder to communicate and be understood, and, even more crucially, to be believed.

Behavioural signs that indicate the possibility of sexual abuse of other children or adults may be too readily interpreted by professionals as due to the disabling condition. For too long professionals and society at large have failed to consider abuse as a possible origin of changed, perhaps challenging, behaviours in people with disability and have not considered that such behaviour may provide one means - sometimes the only means - by which disabled people can communicate their anger and distress in response to abusive experiences.

Strategies for protection

Many countries have now developed or are developing ways of protecting children and vulnerable adults from abuse both within their families and outside the family by others, including other carers and professionals. Such procedures were set up initially for non-disabled children but the frequency of abuse makes it necessary to extend these procedures to disabled children and adults.

There is now greater understanding that professionals, communities and families must be more alert to the possibility of abuse occurring and ways of responding if abuse is suspected. Additional complexities in doing this may be present in investigating and dealing with the abuse of disabled children and adults, particularly in situations where there are difficulties in communication or where the child or adult has an intellectual impairment. Most legal systems discriminate against children and people with learning difficulties or communication impairments,

although a few successful prosecutions have been brought in such situations. This remains an area where professionals in all disciplines require more training, knowledge and skills.

Again, training and raising awareness of the possibility of abuse and its damaging long-term consequences are essential, particularly for professionals and carers of disabled children and adults.

Sexual education for disabled children is at least as important as it is for other children. Support for families and for disabled people to increase their opportunities for communication where there are speech, hearing or comprehension difficulties should include signs or symbols that will enable disabled people to tell of abuse if it exists.

Because of the long-term damaging effects of abuse, it is important that all survivors of abuse have the opportunity of working through their feelings and experiences, with the support of a trained worker.

It has to be accepted that families cannot always be the best or safest places for disabled children or adults and that alternative provision and care are sometimes needed. This may be only on a temporary basis if appropriate work is done with family members as well as with the survivor of the abuse.

VII. Support in the life cycle

Arising from what families have reported, some useful general principles can be derived.

General principles of support

- Support should always be mindful of the rights of the disabled person
- Support should always be offered on the basis of needs identified either by families themselves or in collaboration with families
- Support should be offered in a way that is appropriate to the individual family
- Support should remain flexible. The mode, amount or timing of support should change as the needs of the disabled person and the family change
- Support should retain a focus on the similarity of needs of the person with the disability and the family to those of others
- Support should maximize the degree of control exercised by the disabled person and the family
- Support should facilitate the integration of the person with the disability and the family into the life of the local community.

While these principles apply throughout the life span, there are specific aspects to the support offered at key stages in the life cycle.

At birth

Many parents have written about their experiences and feelings on learning that they had given birth to a child with a disability. It is an experience that is never forgotten, and one that affects their relationships with other professionals for many years. Many parents are still angry and bitter when they remember the pain caused by the manner in which they were first informed that their new baby had a disability. Although there is evidence of considerable improvements over the past 20 years, many parents still complain of insensitivity, lack of information, understanding and support [5].

Some writers automatically assume that giving birth to a child with a disability will always be seen as a tragedy and that new parents inevitably pass through periods of mourning and chronic sorrow before they finally adjust to the reality of having a child with a disability. Professionals and well-meaning friends try to help the new parents to accept the disability, somehow implying that parents deny that their child has a disability or that they reject the child.

The reality is that parents' reactions vary greatly. Some will already have been told before birth that their baby will have a particular impairment and will have made a conscious decision to continue with the pregnancy. Some will realize at once that there is an abnormality in the baby before anyone tells them. Others will suspect that something is wrong from the behaviour of the staff of the maternity unit or because the hospital procedures are different.

Preschool years and early intervention

Since it is universally accepted that the first five years of a child's life are all important, it is vital that parents of children with disabilities are given every possible support in helping their children's development. The nature and amount of support will vary from family to family, in relation to the needs of the child, the family as a whole and individual members of the family. Each family therefore needs to be aware of what is available and be able to discuss how their needs can best be met.

It is essential that all families should be able to express concerns if they are worried about any aspect of their child's development and that their child should be thoroughly assessed by a multidisciplinary team including doctors, nurses and specialists in child development with a knowledge of assessment of young children. Ideally, such assessments should be carried out in an environment familiar to the child, preferably the child's own home, rather than in the strange environment of a hospital or clinic.

In some countries, specialist child development teams are available to carry out a detailed assessment of the level of development the child has reached in various areas of development (e.g. physical, self-care, social, language development). On this basis, the team suggests activities to assist the child's development that can be carried out at home.

In Kenya, for example, about 30 such teams have been established at the local level to work with families and schools. The teams are themselves supported by the Ministries of Health and Education [27].

At this stage, the team has to have some knowledge of the family situation and to ensure that the suggestions that are made are realistic and manageable. Suggestions for additional family activities, over and above what they would do naturally, should be the outcome of negotiation, rather than prescription. If the parents agree, it may be helpful and informative for a member of the team to visit the family beforehand and to keep in touch with the family to provide support and encouragement and to modify the suggestions if they prove to be unrealistic.

Many of the concerns of families at this point relate to ordinary routines such as feeding and sleeping and the extent to which the baby needs to be treated differently as a consequence of the impairment. At a later stage, they will need support in methods of stimulating the child, the right kind of activities and play materials, playing with other children etc.

Wherever possible, assessment and early intervention programmes should plan for a multidisciplinary input. It is particularly important to include medical surveillance, in order to identify additional complications. Children with Down's syndrome, for example, frequently have additional impairments involving ocular, auditory, respiratory and cardiac functions. Similarly, children with epilepsy may not obtain access to the right medication. The prevention of secondary impairments is particularly important in children with intellectual impairment. Because these may not be apparent at birth, it is important to provide comprehensive medical monitoring in order to provide timely and effective treatment. It is sometimes difficult to obtain full medical check-ups, as parents' concerns tend to be dismissed as examples of fussiness or over-protectiveness.

Portage home intervention programme

The Portage home intervention programme is perhaps the best-known example of a home-based family support programme for young children with a developmental delay or disability. This programme was originally developed in rural areas in North America but has since been translated into 30 languages and adapted for use in many developing countries; for example, Guyana, India, Jamaica and Nepal [3].

The Portage programme is based on the parent and home visitor carrying out a joint assessment of the stages that a child has reached in key areas of development; for example, physical, fine and gross motory skills, social, emotional and language development and in a range of spontaneous play activities. This joint assessment is based on the parents' detailed knowledge of the child, supplemented by the home visitor's own observations and experience of other children's development.

The next stage involves discussion and negotiations between the parent and the home visitor concerning priorities for the next steps in the child's learning and, above all, of ways in which the family can help the child to reach these targets in a comparatively short time, within one or two weeks. To this end, the home visitor uses a set of activity cards that suggest ordinary games that can be used by members of the family to help the child achieve short-term targets, mainly using ordinary household routines and activities.

A range of other home-visiting and support programmes have been reported in a number of developing countries. One of the best known of these is the Zimcare project, which has been developed by a voluntary organization in four rural areas in Zimbabwe [18]. These were run in association with existing locally active organizations (e.g. the Red Cross).

While independent evaluation suggested that this was a successful programme, it is clear that not all families and primary-care givers can commit time and motivation to meeting the demands of such programmes. This raises a general issue about the commitment needed to implement Portage-type programmes by families who are already overwhelmed by the day-to-day demands of work and never-ending domestic tasks. There is also the issue of the nature of the participation demanded by the programme. Even when adapted to suit local conditions, family members (nearly always mothers) have to find time to be alone with the child, to record progress (however simply) and to plan further activities with the home visitor.

It is important for those developing such programmes to take account of the potential resources of the extended family and to adapt them to whatever extent is practicable and desirable. Many grandparents, uncles and aunts and brothers and sisters have become involved in early intervention programmes and have played a major part in helping to give families a sense of common purpose in working together to help children with disabilities to learn and to develop and to be accepted in the neighbourhood and the local community.

Inclusion in mainstream preschool programmes

In addition to specialist initiatives such as Portage, it is important to create opportunities to enable preschool children to be integrated into whatever programmes are available to other preschool children. Many countries have developed a range of preschool facilities: nursery schools, nursery classes in primary classes and day-care centres, as well as many privately run kindergartens and playgroups, often run or controlled by the parents themselves.

Many children with developmental delays and disabilities have been successfully integrated into these programmes. There can be no doubt that they provide a much-needed source of support for parents. Not only do they provide a break from the day-to-day care of the child, but they also provide opportunities for meeting other parents and professional staff on a day-to-day basis, with whom they can exchange ideas and experiences.

Yet preschool provision is not common in developing countries. A summary of provision in Asia indicates that only India, Sri Lanka and Thailand have extensive provision [17], though China seems to be rapidly extending nurseries and including children with developmental delays. There are reports of an experimental integration programme in Anhui Province, with some support from the United Kingdom charity, Save the Children Fund.

Towards partnership with parents

In all projects involving young and preschool children, the utmost care is needed to ensure that professionals and volunteers work with and through full and equal partnership with families at every stage. Parents have frequently complained that professionals have a tendency to take over and to know best, forgetting that it is the family who lives with the child for 24 hours a day and has the experience of understanding and trying to meet the child's needs. Professionals are there to support not supplant families.

In countries where comprehensive assessment and early intervention programmes are available, it is important to ensure that parents are not overwhelmed and confused by conflicting advice from different professionals whom they encounter in clinics or on home visits. To avoid this, many teams have developed the concept of a key worker. After the initial assessment, this person provides a single point of contact between the family and the rest of the team. A close relationship develops between the family and the key worker who must be a good listener and mediator, whatever other qualifications they may have. Sometimes this function is carried out by another parent.

Services need to be planned and delivered in order to respond to these individual needs. Services must not be delivered in inflexible packages or be based on a stereotype of family needs and priorities. These have to be discussed and negotiated.

The same dynamic interaction between the needs of families and the nature of available services and supports applies at all stages in the lives of families who have a disabled relative.

School years

In many developing countries, disabled children do not go to school at all. Surveys conducted by the United Nations Educational, Scientific and Cultural Organization (UNESCO) indicate that less than 2 per cent of disabled children attend any form of school in many African and Asian countries and that few of those who do so will complete four years of primary education [12]. Yet studies in a number of countries have indicated that a certain amount of casual integration does take place. Children have been accepted by the local school, because their parents have taken them and because they and their families were already known to the school ([21] and [22]).

Integration dilemmas

In Western countries, it is widely agreed that all disabled children should attend the same local schools as other children in the neighbourhood. This is probably the view of most parents of younger children and of many parents of older children as well.

But the issues are far from simple from the point of view of families and the children themselves. While the inclusion of children with physical impairments is widely accepted, teachers are less ready to accept children with significant learning or behavioural difficulties and are anxious about teaching children with sensory impairments without additional resources provided by equipment or trained support teachers.

Many industrialized countries have a well-resourced and highly developed special school system, with well-trained staff and staff ratios as low as one adult to three children in some classes. The classrooms are often well equipped and the schools are likely to be visited by speech therapists, physiotherapists, medical and nursing specialists and advisory teachers and psychologists.

Yet however well resourced a special school may be, it still separates its pupils from other children and therefore deprives them of the opportunity of a shared learning environment with other children and of helping them in turn to value and include disabled children. The challenge is one of integrating and combining the educational advantages of special schools with the social benefits of ordinary schools; some call this making ordinary schools special and special schools ordinary.

Many links have been developed between special and ordinary schools. Children from special schools may spend part of each week attending classes in a neighbouring ordinary school. Ordinary schools have in turn set up special classes or developed resource rooms and learning support teams to enable children with disabilities to spend all or most of their time in the ordinary class, with carefully planned support from other teachers.

It is tempting to advise parents in developing countries to avoid the mistakes of developed countries by adopting integrated education from the outset, which is indeed the preferred option for many parents. Others however feel that ordinary schools are simply not ready or properly resourced to meet the needs of children with severe disabilities, particularly those with severe intellectual impairments. Teachers may be hostile or negative, the classes are likely to be too large and the needs of such children may be overlooked. In this situation, some parents prefer to put their energies into lobbying for a special school to be set up, often with funds that they have raised themselves or with limited support from public funds. Many parents have set up their own schools and indeed trained to teach in the schools themselves.

Home-school links

Whether children go to school or not, parents and the wider family are just as much in need of support then as they were during the first few years of the child's life. Some will need support in insisting on the rights of their child to attend school. Others may not be convinced that there will be any benefit in their child attending school. They may feel that little or nothing can be done by schools to help the child and they may fear that the child will be teased, mocked or unhappy both in the classroom and in the playground.

In cases where children do attend school, the development of an active partnership of equals between parents and professionals must be a top priority. Unfortunately, this is far from being a reality in many countries, developing or developed. Indeed, it may well constitute the exception rather than the rule.

In many countries, parents of all children, and not just those with disabilities, are still kept at arm's length by schools. Failure to mobilize the interest of parents and to work for their close involvement in the life of the school and the education of their child is a tragic waste of human resources and family commitment.

Where disabled children are concerned, there is everything to gain from developing close working relationships between teachers and parents and other family members. The rationale for such partnerships is overwhelmingly convincing but, with some notable exceptions, not many examples are to be found throughout the world.

Some years ago, UNESCO commissioned ILSMH to prepare guidelines for collaboration and partnership between parents and professionals working with disabled children and young people [23]. The guidelines reflected the best examples of good practice available from reports by some 70 member societies throughout the world.

The main recommendations concerning school-age children are summarized below. They appear to be relevant to different degrees to children with a wide range of disabilities and to schools and families in many countries.

Guidelines for collaboration between home and school

- There should be opportunities for parents and teachers to discuss their aims and priorities for the child, both in the long term and the short term.
- In order to plan the most appropriate curriculum, teaching objectives and methods, teachers should try to learn about the child's home environment in general and as it relates to the child's learning opportunities in particular.
- Teachers and family members should jointly assess the child's skills, abilities and needs.
- Successful collaboration between parents and teachers depends on the extent to which information is shared.
- Educational goals and methods need to be shared with families.
- Parents and teachers should share and celebrate success.
- Teachers need to find the time to listen to parents' concerns and priorities ("Your choice is our choice", as expressed by teachers in Bangladesh).
- It is useful for parents and teachers to list possible ways in which they can work together; for example, through teachers visiting parents at home, parents taking part in school activities, recording of children's work through photographs and videos to illustrate progress or share ideas on joint work.
- Parents can be much more fully involved in training professionals.
- Opportunities need to be created to involve both the parents and the student in the formulation and monitoring of plans and policies at the level of the school and in the locality.

Needs of school-leavers and young adults

The age at which children leave school varies greatly across the world, both for disabled and non-disabled children. In many countries, the majority of children do not complete even four years of primary education and can expect to leave school between 10 and 12 years of age. Many drop out after one or two years and others only attend sporadically. Only a minority proceed to secondary education or beyond.

If this is the norm for many children in developing countries, it is all the more important that a firm foundation of partnership is laid between parents and teachers during the years when children are at school. Many parents will be able to build on these foundations once their child leaves school and transfer what they have learned from this partnership to new challenges and situations that the family will encounter as their son or daughter leaves school and becomes an adult.

Leaving school presents challenges both to the young person and to the family. The routine of daily attendance at school and the structure that this provides are suddenly disrupted. The young person often feels disorientated and confused by the change of routine and lifestyle and may be left with little or nothing to do during the day. It may take time to find a useful role and to adjust to the changes brought about by leaving school.

All this may coincide with the whole range of social, physical and sexual pressures associated with the normal process of adolescence, in this case complicated by disability and by doubts and uncertainties about the future.

The family will also be faced with a number of adjustments. All too often, a member of the family, usually the mother, is forced to give up her work or some of her outside interests, in order to look after a disabled son or daughter. This in itself can be a cause of stress, all the more so because in most countries the prospects of daytime occupation for young disabled people are small. The family situation is therefore potentially tense and explosive.

It is at this time that worries about the long-term future can become prominent; concerns about what arrangements can be made for the young person when the parents are too old or themselves too disabled to look after their son or daughter and what will finally happen after their death. This is a particular concern in cases where the young person is severely intellectually impaired and needs a level of support and care that is not available in the community.

In some countries, housing trusts have been set up to ensure that a home can be provided with appropriate levels of care when this becomes necessary. Parents who can afford to do so may make payments into a trust fund specifically set up for this purpose. Sometimes, all too rarely, plans are made by public authorities to prepare the young person to live in alternative accommodation in the community when the time comes. But schemes such as this are only available to the few and many families cannot see any resolution to this problem and fear that their son or daughter may be sent to an institution for the rest of their lives.

Planning for the future

There are few countries in the world where provision for disabled school-leavers and young people meets the whole range of needs identified at this time in the young person's life or where it is planned in partnership with the family. In most countries, even families who have been reasonably well supported while their child was at school are often neglected and left to fend for themselves. Because few services are available for the young people themselves, the situation at home can be highly charged and reach crisis point.

Families need to be able to voice these concerns and to know that they will not only be listened to with understanding, but also that plans will be made with their full participation as well as that of the young people concerned, which will result in an exploration of whatever alternatives are available, however limited these may be.

This process needs to begin while the young person is still at school. In some developed countries, there are legal requirements for a transition plan to be developed for all disabled school-leavers. The school is not only responsible for preparing the young person to be as independent as possible, but also for involving parents and the student in discussion and decision-making on future provision, together with other professional staff such as social workers and health professionals who are well placed to advise on these options. Increasingly, schools are helping their students to anticipate some of the problems they will face in finding a job and taking their place in society.

The first need of families is for information about facilities and resources that are or can be made available, however limited these may be. In some countries, this information is summarized in leaflet form, listing the names of key organizations and individuals. These agencies may be scattered and uncoordinated, making it difficult for families to know where and how to begin to secure the support and services that they and their son or daughter need.

Because families are at their most vulnerable at this transition point between school and community services, it is essential to ensure that one person is designated as a single point of contact and that families should have a say in choosing him or her. This person should then try to coordinate the information available from the various agencies and act as a friend or advocate of the family in securing the most appropriate provision for the family as a whole and for the disabled person in particular. Their needs are now, as before, inseparable.

Continuing education

In many developing countries, continuing education facilities are becoming available to disabled young people. These are usually in local community colleges attended by other young people and provide a wide range of vocational and non-vocational courses.

Such colleges provide a fresh start both educationally and socially. Many young people who have attended special schools or classes are more than ready for the more adult and challenging environment that can be presented by a local college.

As most colleges are by definition for all members of the community, the initial assumption is that disabled students will be fully included in the classes of their choice. This means that college staff will need some preparation and support in ensuring that the curriculum and activities of the class and of the college as a whole are fully extended to all disabled students. Some students will need additional support; for example, access to and mobility within the building, taped or Brailled material, sign-language interpretation and learning support. Some of these supports are expensive; others call for a greater degree of awareness, knowledge and skills among all levels of college staff.

The role of parents whose son or daughter is attending college is an ambiguous one. Although they have a great deal of valuable information to share with the college, it is likely that their sons or daughters will be of an age when they ought to be able to speak for themselves and make their own needs known. Staff may therefore be inclined to keep parents at arms's length, in the interests of consistency with other students whose parents may have little or no formal or social contact with the college.

It is important, therefore, that parents should at least be centrally involved at the time of admission to the college. At this stage, other professionals such as teachers, health professionals or social workers may also be involved with the young person and the family in developing a transition plan in collaboration with college staff. Parents should then have an opportunity of sharing their views and information on a basis of equality with other partners in the transition process.

Because choosing the right courses is one of the most difficult decisions facing any student entering college, it is essential that all concerned are made aware of what is available and that the choice really meets the needs of the student who should have the final say. There is a risk of underestimating the student's abilities and of assuming that certain courses may be too difficult for one reason or another or that vocational courses may not lead to employment at the end of the course. Family members, college staff and former teachers may all have different views. In this situation, the voice of the student is sometimes drowned in a chorus of well-intentioned advice.

Preparation for employment

Despite world recession and high levels of unemployment, disabled people insist on their rights to paid employment. This is in line with International Labour Organisation Convention 159 of 1983 concerning Vocational Rehabilitation and Employment (Disabled Persons) [14] and also with the Standard Rules on the Equalization of Opportunities for Persons with Disabilities [30]. A small number of countries have introduced legislation making it illegal to discriminate against disabled people in respect of employment, as well as housing, education, leisure, transport etc. (e.g. the Americans with Disabilities Act, 1990). Others have introduced disability quotas and levies (e.g. Germany).

In reality, the number of disabled people in full employment is very low in most countries. Nevertheless, a growing number of disabled people have found and kept jobs, despite the underestimation of the likelihood of their doing so by families or professionals.

In developing countries, many disabled people are working with their family, especially in rural areas. In other cases, they are working in family businesses or selling goods from a family stall in the market-place. This not only benefits the individual and the family, but also provides a good example to the general public that disabled people can make a positive contribution to society.

In other cases, parents and voluntary organizations have themselves set up sheltered workshops and vocational training centres to ensure that disabled people have access to some form of training and vocational preparation (e.g. Kenya). Some of these workshops specialize in making certain products and then marketing them directly to the general public. This aim may at times conflict with that of preparing people to work in the open market or at least of securing supported employment.

Many industrialized countries have long established day centres or sheltered workshops but their success in placing people in open employment is limited. A number of countries, however, have reported successful schemes where a disabled person is given whatever support is needed to enable them to do a particular job in a given environment. The support may be in the form of grants for the employer to adapt the workplace or for individuals to acquire physical or electronic supports to enable them to operate machinery or to carry out tasks that would otherwise be difficult or impossible for them.

In some countries, human support is given to enable a disabled person to learn and become proficient in the tasks required in the work setting. This support is sometimes provided by a staff member from the day centre or sheltered workshop or by a volunteer from the workplace who provides essential social support in helping particularly those with intellectual impairments to make friends and join informal social networks (e.g. the Pathway scheme in the United Kingdom, started by the voluntary agency, the Royal Society for Mentally Handicapped Children and Adults (MENCAP) but later developed from public funds).

Living in the community

In developed countries, the principle of living an ordinary life implies that disabled people should be supported in leaving their families and living as independently as possible. Some progress has been made to this end. An increasing number of adults, including some with severe physical and intellectual impairments, are living in their own homes and apartments, with as much support as they need as individuals. This comes from publicly funded social-care assistants who help them with those tasks and activities that they cannot carry out for themselves.

In most developing countries, however, it is traditional for young people to remain with their families until they marry. In these situations, the concept of moving out of the family in late adolescence would not be considered appropriate, as the family expects to provide a home for some years and also to include new daughters-in-law as the sons marry, at least for a period. Furthermore, the extended family has a key role in supporting all members of the family, including those with a disability. This may include a job and a home being provided by a member of the extended family. Although a greater number of small nuclear families are now found in developing countries, the traditional supporting role of the extended family remains strong in most countries.

Marriage and parenthood

Disabled people often have restricted opportunities to meet people of their own age and background. Similarly, families of young disabled people may over-protect their son or daughter and discourage friendships and more intimate relationships, for fear of exploitation or disappointment.

In the past, there has been little open recognition of the sexual needs of disabled people and of the fact that these are no different from those of the rest of the population. Disabled people, particularly those with intellectual impairments, have been regarded as asexual both by their families and by professionals, despite clear evidence to the contrary. Consequently, sexuality, sex education and support in personal relationships generally have rarely been provided for young people or discussed by their families.

More recently, the social and sexual needs of disabled people of all ages have received increasing recognition, stimulated in part by growing evidence of their vulnerability to exploitation and sexual abuse as well as by the more positive motivation of supporting them in forming relationships, in marrying and in becoming parents.

Recognizing, respecting and supporting disabled people in forming relationships, marrying and becoming parents again calls for understanding and collaboration between disabled people themselves, their families and the various professionals with whom they may be in contact. Although many disabled people will need relatively little help, others, particularly those with intellectual or communication impairments, may well encounter greater obstacles and need sensitive support.

Many disabled people marry and become successful parents, and some marriage partners and some parents may become disabled when they already have a family. Again there will be a great variety of experience, just as among the non-disabled population and depending on the social environment.

Although many disabled people have married and become parents, they face many obstacles. In part these spring directly from cultural and social attitudes to disability. For example, there may be fears about the extent to which the disability may be inherited and may be passed to children, or there may be concerns about the ability of the disabled person to support a family.

Disabled people who have pioneered by pressing for their right to share these common human experiences have helped to shape society's thinking on these issues and some disabled parents and some children of disabled parents have begun to document their experiences.

Challenge of ageing

The increasing life expectancy both of disabled people and their parents is bringing new challenges. It is not uncommon for ageing disabled people themselves to become carers of their elderly and infirm parents. This may provide a valued and indeed indispensable role for them, but it also creates barriers to their own independence and autonomy in the community. Their situation parallels that of countless women who have sacrificed opportunities for a career, marriage and motherhood in order to devote themselves to the care of their or their spouses' elderly and dependent parents.

Some disabled people enter willingly into such a role but others will feel that new restrictions are being imposed on them against their will. It is important, therefore, that these issues are considered by the whole family in advance of emergencies and that the disabled member of the family should express a clear view and take appropriate action. Families should expect to receive support from professionals and service agencies in the community.

The process of ageing can be particularly difficult for disabled people. It is all too often assumed that any physical or psychological difficulties that they experience are an integral part of their disability. When this happens, they may find it hard to obtain investigation and treatment for conditions that are not directly related to their disability at all.

A further dilemma arises in individuals with Down's syndrome who show signs of rapid ageing consistent with Alzheimer's disease at a comparatively early age. Although many have lived successfully and with varying degrees of support in the community, the ageing process can affect them so severely that some form of residential care becomes necessary. Should they then be integrated into ordinary old people's homes and geriatric hospitals where they will be much younger than other residents and where they might have to live in poor conditions for many more years? A preferred solution is to provide them with an increasing amount of support to enable them to remain either in their own homes or in supported accommodation. Funds for this option are hard to come by.

Preparing for death and bereavement

Children and adults with disabilities are as, or perhaps even more, likely to experience the death of their relatives, carers and friends as anyone else. They themselves may have a progressive, terminal condition. It may be particularly painful for carers to explain and prepare disabled people for death and bereavement, as well as to support them through their grief and mourning. This is understandable when attachments may be all the more crucial because of the additional dependency needs. However, it is all the more important to involve the disabled person in what is happening, to explain and to provide opportunities for them to express their feelings, fears and anxieties as well as the confusion, anger and powerlessness that are well-known features of bereavement. Giving information and explanation, and involvement in planning for their own future, are all ways in which those supporting disabled people can enable them to retain as much control over their own lives as possible.

VIII. Conclusions

Disabled people themselves and their families have already made and are continuing to make a significant and powerful impact on the way the societies in which they live think about and respond to disabled people. An increasing number of disabled people are making an outstanding and inspirational contribution to the life of their communities as teachers, politicians and artists. The various United Nations conventions and charters and guidance to Governments in relation to disability issues are a useful spur to further action. But profound changes are needed before disabled people are granted equal rights and can fully take their place in society and, most importantly, before society itself can fully benefit from the creativity, strengths and abilities of disabled people and their families. IYF can provide a starting-point for a major reappraisal of the extent to which families can be better supported in helping their relatives to take their place in the community and to make a significant contribution to society.

In preceding sections, the focus has been on individual families and services to support people with disabilities and their families in particular. But what disabled people and their families most want is to have the same access and rights to life-enhancing opportunities as their non-disabled friends and neighbours. In order for this to be possible, the needs of disabled people must be considered alongside those of all other groups.

For this to happen, the built environment will need to change to enable disabled people to become as mobile and as able to use buildings, transport and other facilities as everyone else.

Education, employment, housing, health, social welfare, income security and all other services must also become as accessible to disabled people and to members of their families as to all other members of society.

Above all, social attitudes in all cultures must become informed by true knowledge about disabled people and their families, their strengths, their needs, their difficulties and their gifts.

These changes can come about in a variety of ways through:

- National and local policies and social education
- A more informed portrayal of disabled people and their families by the media
- A greater degree of interaction between disabled people and their families
- The perseverance of disabled people, their families and supportive professionals in continuing to campaign for all these necessary changes.

More positive social attitudes, policies and structures will bring about a greater contribution from disabled people and their families. This in turn will provide a foundation for the achievement of the goal of a Society for All in the twenty-first century.

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Annex

LEARNING MESSAGES

The Learning Messages that the IYF Task Force of ILSMH wants to communicate to its member societies, and to Governments, international agencies and to all individuals and organizations concerned with IYF are as follows:

- (a) All people are valued members of their communities;
- (b) People with a disability and their families are equal participating members of their communities and have the same rights:
 - (i) To participate in decisions that affect their lives;
 - (ii) To diversity of choice of housing, education, work, recreation and leisure;
 - a. To equity and justice;
 - b. To be empowered to take their full place in the community;
 - c. To dignity and privacy in all aspects of their lives;
- (c) Everyone is likely to experience disability at some time in their lives, either personally or through members of their family or community;
- (d) Society can add to or lessen disability;
- (e) People with disabilities have abilities;
- (f) People with a disability have the right to be consulted, to make informed choices and to exercise control in planning their lives;
- (g) People with a disability and their families and carers have an important contribution to make to policy development, planning and delivery of services and to training about disability issues;
- (h) It is normal to be different;
- (i) People with a disability have useful knowledge about their own needs, strengths and abilities;
- (j) Families with a member who has a disability have knowledge about their own strengths, needs and abilities;
- (k) Families need information;
- (l) Support for families with a member who has a disability makes economic sense;
- (m) Definitions of the family must reflect the wide range of family arrangements and forms found in society;
- (n) Usually it is in the best interests of the family member with a disability to remain within the family environment, at least during childhood. Families require practical support in order to fulfil this role. Exploitation of families by the State needs to be avoided;

(o) The interests, safety and welfare of the person with a disability must always be safeguarded;

(p) In two-parent families, the task of caring for a family member with a disability should as far as possible be shared by both parents. Fathers and mothers both have a vital role in creating a beneficial family environment. Both can make a valuable contribution to the functioning of supportive organizations and where possible should be actively involved in such organizations.

